



“Marks and scars”

Hepatitis C and people who inject drugs:
The family experience

July 2017



Contents

| | |
|---|----|
| Literature Review | 3 |
| Introduction | 3 |
| Hepatitis C in the UK | 3 |
| Experiences of living with hepatitis C | 5 |
| Families affected by a loved one's drug use | 8 |
| Hepatitis C and Families | 9 |
| Methodology | 9 |
| The family members | 9 |
| Knowledge | 9 |
| Worry | 11 |
| Testing | 12 |
| Impact on family life | 14 |
| Katie's story | 19 |
| Seeking information and support | 20 |
| Accessing treatment | 23 |
| Improving families' experiences | 25 |
| Conclusion | 29 |

Adfam is the national charity working to improve life for families affected by drugs and alcohol. We do this through empowering family members and carers, supporting and training frontline workers, influencing decision-makers and campaigning for improved family support services nationally and locally. We want anyone affected by someone else's drug or alcohol use to have the chance to benefit from healthy relationships, be part of a loving and supportive family and enjoy mental and physical wellbeing.

This report sets out the impact hepatitis C has on family members of people who inject drugs. It comprises a review of the available literature followed by the findings of Adfam's research on this issue. We would like to thank all of the family members who shared their experiences with us and Gilead Sciences for supporting this report with a research grant.

Literature Review

Introduction

Hepatitis C is a blood-borne virus which predominantly affects the cells of the liver and is spread by direct exposure to infected blood, for example by sharing needles. It has become known as a 'silent killer'; an individual can have it for years without any symptoms, or its symptoms, such as depression, fatigue, skin problems, pain and digestive problems, can be attributed to other causes.

Despite the prevalence of hepatitis C, relatively little is known about it among the general public. Its impacts, however, can be far-reaching. Not only can it be fatal, sometimes causing fibrosis and cirrhosis of the liver, liver cancer or end stage liver disease, but it can also have other detrimental impacts on the individual who has contracted it, and those around them.

Adfam has been funded by Gilead Sciences to research the impact of hepatitis C on the family members of people who inject drugs (PWID). Their experiences are largely unknown, and this research begins to fill that gap.

Hepatitis C in the UK

A recent report from Public Health England (PHE) stated that an estimated 214,000 people are living with chronic hepatitis C in the UK. Intravenous drug use is the most important risk factor for infection. Around half of PWID are thought to be infected in England and Wales, with levels being lower in Northern Ireland (23%) but higher in Scotland (57%).¹ While those who inject drugs are most at risk of contracting hepatitis C, it can also be transmitted by sharing other drug paraphernalia such as crack pipes or straws.

Hepatitis C was the most common infection among PWID in 2015, with two in every five people who inject psychoactive drugs living with chronic hepatitis C. Of those who inject image and performance-enhancing drugs, around one in twenty have hepatitis C.² Current levels of transmission among young or new injectors suggest that hepatitis C virus (HCV) infection is often acquired relatively early in an individual's injecting career,³ meaning that even those who have not injected drugs over a sustained period of time are still at risk of infection. Numbers of new HCV infections have remained relatively stable over recent years.⁴ However, despite intravenous drug users being one of the groups most at risk of contracting hepatitis C, only around one half of PWID sampled in UK surveys were

1 Public Health England (2016) *Hepatitis C in the UK 2016 Report*, London. p.9

2 Public Health England (2016) *Shooting Up: Infections among people who injected drugs in the UK, 2015, An update: November 2016*, London. p.4

3 EMCDDA (2016) *Drug-related infectious diseases in Europe*, Luxembourg. p.6

4 Public Health England (2016) *Hepatitis C in the UK 2016 Report*, London. p.8

aware of whether or not they have been infected. This figure has remained relatively stable over the last five years.⁵

Recent research has suggested that there are a variety of reasons which have led to a delay in diagnosis: “*limited HCV relevance, felt wellness, stigma, compartmentalization of former injecting practices, unexplained symptoms and general practitioner inaction.*”⁶ A 2017 report by The Hepatitis C Trust has suggested that raising public awareness of hepatitis C will be vital in increasing the number of people who get tested, and thus diagnosed.⁷ The early diagnosis of HCV infection is important so that people can access the most effective treatment and care.⁸ PHE has recommended wider rolling out of testing to more individuals at risk of infection, including to PWID.⁹ It has also recommended introducing initiatives to further raise awareness of hepatitis C among professionals in primary care and other settings.¹⁰

In May 2016, the UK Government pledged its support for the World Health Organisation’s goal of eliminating hepatitis C as a major public health threat by 2030.¹¹ The WHO Global Health Sector Strategy sets out targets to work towards this goal.¹² These include reducing new cases of chronic HCV by 30% by 2020 and 80% by 2030, and diagnosing 30% of people with HCV by 2020 and 90% by 2030. In order to meet these targets, Public Health England believes there needs to be a radical change in the response to hepatitis C among PWID.¹³ Raising awareness of hepatitis C will be a major part of this, and PHE has called for more to be done to increase diagnoses, ensure easier access to testing and treatment and further develop care pathways and support for people with HCV.¹⁴

There is agreement that the ambitious goal of eliminating hepatitis C as a public health threat by 2030 is not unachievable; the treatment landscape has dramatically changed over the last few years. Previously, standard treatment of hepatitis C was limited to interferon-based treatments. These had low success rates and often severe side effects. However, the introduction of direct-acting antivirals (DAAs) to treat hepatitis C has promised hope; they have cure rates of up to 90%, are shorter treatments and have far fewer side effects. The Hepatitis C Trust’s patient helpline reports that patients with experience of both old and new treatments are significantly more positive about the newer drugs, with many of them able to continue their lives as normal while undergoing treatment.¹⁵ Currently, however, NHS England has decided to limit DAA access in the UK to 10,000 people per year, despite the National Institute of Health and Care Excellence recommending them as ‘cost-effective’ in 2015. The Hepatitis C Trust unsuccessfully made a legal challenge against this decision, arguing that the new treatments should be available to all.

5 Ibid.

6 Harris, M.; Ward, E.; Gore, C. (2016) *Finding the undiagnosed: a qualitative exploration of hepatitis C diagnosis delay in the United Kingdom*. Journal of Viral Hepatitis 23. p.479

7 The Hepatitis C Trust (2017) *Patient Perspectives Report 2017*, London. p.9

8 Public Health England (2016) *Hepatitis C in the UK 2016 Report*, London. p.13

9 Ibid. p.14

10 Public Health England (2017) *Hepatitis C in England 2017 Report*, London. p.10

11 The Hepatitis C Trust (2017) *Patient Perspectives Report 2017*, London. p.7

12 Public Health England (2016) *Hepatitis C in the UK 2016 Report*, London. p.25 (Appendix 1)

13 Ibid. pp.8,21

14 Ibid. p.6

15 The Hepatitis C Trust (2017) *Patient Perspectives Report 2017*, London. p.16

PHE stated in its recent report that as the new treatments are rolled out, a rapid reduction in severe morbidity and mortality is expected.¹⁶

In 2016, Gilead Sciences launched the *I'm Worth...* campaign, a disease awareness programme aimed at addressing the stigma that many people with hepatitis C face, and encouraging and empowering those living with hepatitis C to access care and services no matter how or when they were infected.¹⁷

Experiences of living with hepatitis C

Research has shown that living with hepatitis C can have a severely detrimental impact on the individual, and this impact is not just confined to the physical symptoms and risks posed by subsequent health conditions.

Reaction to diagnosis

The reaction to the diagnosis among patients can vary. One study in Australia found that *"participants were almost evenly divided between those who described the diagnosis as distressing and those who reported being unconcerned."* It found that most of the people who were not concerned about the hepatitis C diagnosis also reported regularly injecting drugs at the time of diagnosis.¹⁸

A recent report from The Hepatitis C Trust found that the distressing nature of the diagnosis was compounded by a lack of provided information, leading patients to conduct their own research online, and receiving the news that they had tested positive in an unsuitable manner, for example over the phone or by a receptionist.¹⁹ This report found a lack of awareness of hepatitis C among patients, members of the public and health professionals and recommended patients being given clear and comprehensive information upon diagnosis.²⁰

Despite the increased hope following the introduction of DAAs, their rationing has been found to have a negative impact on patients following diagnosis. Another report from The Hepatitis C Trust, this time researching the perspective of nurses, found that nurses are concerned about their patients' mental health as a result of delays to treatment, with the inability to access treatment reinforcing low self-esteem among patients and leaving them feeling "very upset" and "in limbo".²¹ The rationing of DAAs has led to clinicians being advised to "manage patient expectations" about the benefits of a HCV cure, but recent research has suggested that these benefits are not merely physical, and so should be taken into account as well.²²

16 Public Health England (2016) *Hepatitis C in the UK 2016 Report*, London. p.17

17 Gilead Sciences Ltd. (2016) *I'm worth...* [online] Available at: www.imworth.co.uk/ [Accessed 28/4/2017]

18 Harris, M. (2009) *Troubling biographical disruption: narratives of unconcern about hepatitis C diagnosis*. *Sociology of Health & Illness* Vol. 31 No. 7. pp.1,4

19 The Hepatitis C Trust (2017) *Patient Perspectives Report 2017*, London. pp.13-14

20 Ibid. pp.3-4

21 The Hepatitis C Trust (2017) *Nurses' Perspectives Report 2017*, London. p.5

22 Harris, M. (2017) *Managing expense and expectation in a treatment revolution: Problematizing prioritisation through an exploration of hepatitis C treatment 'benefit'*. *International Journal of Drug Policy*, in press.

Stigma

A common theme in research into experiences of living with hepatitis C is stigma, which can have a variety of negative effects on people. Very often, this stigma is an extension of the stigma surrounding substance use, due to the association of HCV infection with injecting drug use.²³ Stigma has been found to have a detrimental impact on quality of life, with fear around disclosing and transmitting HCV infection, and difficulties in employment and sexual relationships.²⁴ This stigma can be concealed, due to the invisible nature of hepatitis C.²⁵

A 2016 qualitative study into diagnosis delay in the UK found that stigma was a key factor; one participant reported not being asked about drug use by their GP – and put that down to the stigma which surrounded the issue: *“No GP has ever said ‘Have you used drugs?’ because there was a huge stigma and there still is a huge stigma.”* Another described not wanting to know because of *“The shame of it... I think what I’d put my family through... maybe I didn’t want to go back to it being so long ago, it [my drug use] was 30 years ago.”*²⁶ Stigma was often felt to be perpetuated due to an absence of HCV resources and limited visibility of HCV as a public health issue, making those with the virus seem unimportant.²⁷

A 2009 New Zealand study into HCV stigma found that one participant had internalised societal stigmas about injecting drug use to such an extent that he viewed his hepatitis C diagnosis as a moral designation which put him off from telling friends,²⁸ and another regarded herself as dirty due to comments from her mother: *“She goes, ‘Don’t tell any of my friends, because it’s dirty. I mean everyone knows that you get that from using needles.’”*²⁹ Often the stigma was exacerbated by misconceptions about infectivity; one woman recounted being told by a nurse in a hospital that she was not allowed to use the bath due to having hepatitis C.³⁰ Other research has suggested that the health care setting is the most common site of experienced HCV discrimination by PWID, potentially because this is where people are most likely to disclose their HCV status.³¹

Likewise, a 2012 qualitative study into barriers to hepatitis C treatment for PWID found that stigma played a part, with one man saying *“Hep C, it’s much more of a stigma about injecting and being an injecting drug user and therefore, it’s dirty, you know, you’ve got it yourself, you’ve gone out and got it.”*³² Several participants were reluctant to tell others

23 Harris, M.; Richters, J. (2006) *Psychological aspects of living with hepatitis C*, Social Research Briefs: Number 8, p.1

24 Ibid.

25 Harris, M. (2009) *Injecting, Infection, Illness: Abjection and Hepatitis C Stigma*. Body & Society Vol.15 (4). p.37

26 Harris, M.; Ward, E.; Gore, C. (2016) *Finding the undiagnosed: a qualitative exploration of hepatitis C diagnosis delay in the United Kingdom*. Journal of Viral Hepatitis 23. pp.481-2

27 Ibid. pp.482,484

28 Harris, M. (2009) *Injecting, Infection, Illness: Abjection and Hepatitis C Stigma*. Body & Society Vol.15 (4). p.39

29 Ibid. p.43

30 Ibid. p.44

31 Harris, M.; Rhodes, T. (2013) Hepatitis C treatment access and uptake for people who inject drugs: a review mapping the role of social factors, Harm Reduction Journal 2013, 10:7. p.4

32 Harris, M.; Jolly, E.; Martin, A.; Wells, H.; Rhodes, T. (2012) *Barriers and facilitators to hepatitis C treatment for people who inject drugs: A qualitative study. Technical Report*. World Health Organization, Copenhagen. p.26

about their hepatitis C diagnosis: *“it’s just scary to some people”*. This stigma was often a primary motivator to enter into HCV treatment.³³

This study recommended increasing HCV awareness and knowledge among the partners and families of affected individuals so that stigma could be reduced and care could be improved.³⁴ Similarly, a recent report by The Hepatitis C Trust has recommended that the Government implement a public awareness campaign, aimed at tackling stigma and encouraging people to access testing.³⁵

Relationships with other family members

Another key impact of having hepatitis C – which is particularly pertinent to our research – is the effect it has on patients’ relationships with family members and friends.

A qualitative longitudinal study conducted between 2012 and 2015 found a number of social impacts on people living with hepatitis C. Relationships with family members often suffer due to fears about transmission. One man spoke of wanting to be *“back to normal”* because the mother of his son tells him *“Oh no, you don’t see your son, because it’s infectio[us]”*³⁶, another was told *“We all sit at this side of the table and you can sit on the settee over there. Don’t play with the kids too rough.”*³⁷ and another spoke of being reluctant to play with his grandchildren: *“I like to play with them and have a rough and tumble. I haven’t been so close to them since I’ve had it... it’s sad, especially when they jump and try and give me a cuddle.”*³⁸

Another participant spoke of ceasing all sexual relationships, despite HCV rarely being transmitted heterosexually: *“I found out I got hep C... that’s it, my life’s over, that means women are gone... I’m scared of giving it to them and I think to myself, if I can get rid of it I don’t have to worry... It was the biggest [treatment incentive] for me.”*³⁹ Another participant stated that even if his wife had been better informed about the infectivity of HCV, she would still have been concerned about it.⁴⁰ The study found that the physical effects of HCV also had a social impact, with participants citing the effect that a lack of energy can have.⁴¹ Following successful treatments, participants found that they were able to socially reconnect to those around them.⁴²

A 2009 New Zealand study into HCV stigma found other impacts on interactions with family members and friends. For example, some relatives and friends brought their own cups when visiting them or refused bodily contact, while others felt silenced by their friends, family and acquaintances who did not want to hear about their illness: *“social stuff I found*

33 Ibid. p.27

34 Ibid. p.28

35 The Hepatitis C Trust (2017) *Patient Perspectives Report 2017*, London. p.18

36 Harris, M. (2017) *Managing expense and expectation in a treatment revolution: Problematizing prioritisation through an exploration of hepatitis C treatment ‘benefit’*. International Journal of Drug Policy, in press.

37 Ibid.

38 Ibid.

39 Ibid.

40 Ibid.

41 Ibid.

42 Ibid.

*the hardest... people don't actually want to know about chronic illness.*⁴³

A 2012 study documents the impact on family members and friends in a different way; particularly during HCV treatment, participants relied on family members for doing everyday tasks as well as emotional support. One participant felt like she was a burden on her family: *"I've got family support... it makes it even worse really because it makes it harder. You feel like it's all like you ain't just bringing yourself down, you're bringing that ship down with you. It's like you're hurting other people as well. I prefer to be on my own."*⁴⁴

The study also found that caring responsibilities were a challenge for participants undergoing treatment, as they themselves also needed support.⁴⁵ The study recommended support and information about HCV treatment for friends, families and carers of those undergoing HCV treatment.⁴⁶

Families affected by a loved one's drug use

It is estimated that in the UK there are at least 1.5 million adults who are significantly affected by a family member's drug use.⁴⁷ While it is unclear how many of these have family members who inject drugs, an estimated 122,894 people in the UK inject drugs,⁴⁸ meaning that a significant number of family members are affected. Given the prevalence of hepatitis C among PWID (around half in England and Wales),⁴⁹ it is likely that this is an issue which affects a large number of family members.

The experiences of family members are largely undocumented; this research begins to rectify this by shining a light on what it is like to be a family member of someone who injects drug and who has contracted – or is at risk of contracting – hepatitis C.

43 Harris, M. (2009) *Injecting, Infection, Illness: Abjection and Hepatitis C Stigma*. Body & Society Vol.15 (4). pp.44,46,47

44 Harris, M; Jolly, E; Martin, A; Wells, H; Rhodes, T (2012) *Barriers and facilitators to hepatitis C treatment for people who inject drugs: A qualitative study. Technical Report*. World Health Organization, Copenhagen. pp.31-32

45 Ibid. p.33

46 Ibid. p.34

47 UK Drug Policy Commission (2009) *Supporting the supporters: families of drug misusers* [online] Available at: [www.ukdpc.org.uk/wp-content/uploads/Policy%20report%20-%20Supporting%20the%20supporters%20of%20drug%20misusers%20\(policy%20briefing\).pdf](http://www.ukdpc.org.uk/wp-content/uploads/Policy%20report%20-%20Supporting%20the%20supporters%20of%20drug%20misusers%20(policy%20briefing).pdf) [Accessed 28/4/2017]

48 EMCDDA (2016) *Drug-related infectious diseases in Europe*, Luxembourg. p.17

49 Public Health England (2016) *Hepatitis C in the UK 2016 Report*, London. p.9

Hepatitis C and Families

Methodology

Adfam ran two online surveys from December 2016 to February 2017 using a convenience sample. Twenty seven people participated. One survey was for family members of people who have been diagnosed with hepatitis C due to injecting drugs and was answered by 17 people. The other was for family members of people who inject drugs, and are therefore at risk of contracting hepatitis C, but do not have a diagnosis, and was answered by 10 people.

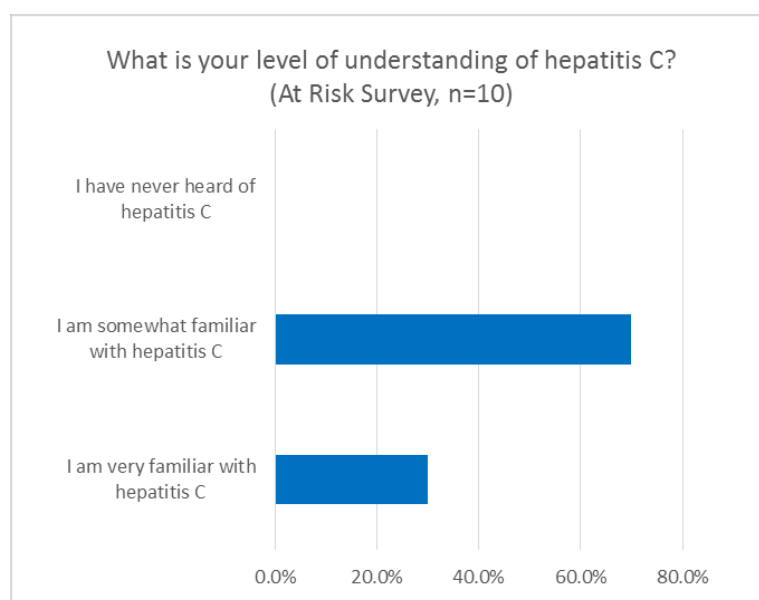
Six phone interviews with family members were conducted between March and April 2017 to go into more depth. Participants were recruited via promotion online, on social media and using Adfam's existing networks. All names have been changed and models have been used for photographs.

The family members

A variety of family members were involved in the research. The family members in the at risk survey were affected by the drug use of their child (5), sibling (3), parent (1) and sister-in-law (1). The family members in the diagnosis survey were affected by the hepatitis C diagnosis of their parent (3), child (3), sibling (5), partner (5) and cousin (1). The family members in the phone interviews were mothers (4) and partners (2).

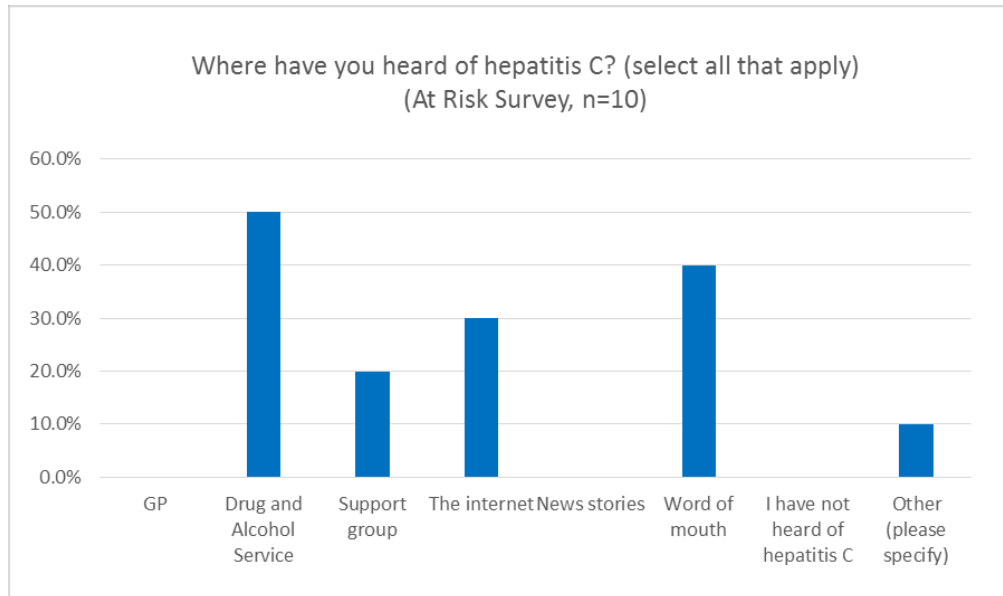
Knowledge

Awareness of hepatitis C among family members of people who inject drugs is fairly high; each participant was at least somewhat familiar with it. One participant told us that they were a trained substance misuse practitioner and so was very knowledgeable on the subject. However, several family members felt that their knowledge was limited.



"[My knowledge of hepatitis C] is not in depth, it's probably more like the average person. I don't have an in depth medical knowledge. I am very much aware of it: I know that it affects the liver, I know that not everybody dies with it, and I know medication has changed a lot over the years."

"I guess I have a basic understanding unless it has changed in the last few years."



Family members had heard about hepatitis C in a variety of places, the most common being from a drug and alcohol service. Others, such as Sue, had heard about it through their own work and experiences:

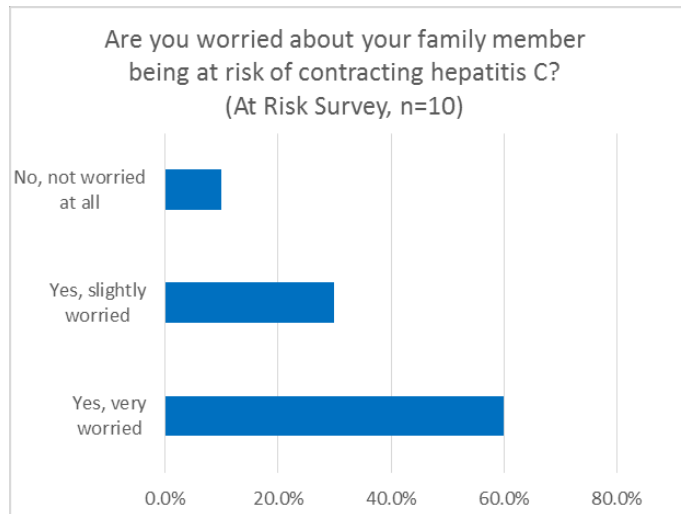
"I've basically heard about it because my sister-in-law died of it 18 years ago. About 25 years ago I was working for a women's refuge and we'd done a lot of stuff – a lot of the women coming into the refuge who had suffered domestic violence had had partners involved in drink and drugs. We had a lot of in-house training around AIDS and drug use and I heard about hepatitis C then."

Carol felt that, while she had heard a bit about hepatitis C, this was not enough to stop her worrying.

"I knew a bit about hepatitis C through [a family support group] but not enough for me to stop worrying, you know about what I mean? We had [the family support group], but no other knowledge about it or way of finding out."

Worry

Concern about hepatitis C was commonplace among the family members who participated in our research, with most saying that they were very worried. A variety of reasons for this worry were given: one person was worried about the potential impact on their brother's partner and child as he is still injecting, while another was worried about their child being re-infected with it despite already having been diagnosed.



"I am massively worried. Interestingly he has just recently come out of hospital, and we had a conversation around this. He was tested for everything when he was in there and told to wait three months before being tested again. His last tests were clear. He went into hospital because he was injecting in his groin resulting in a very nasty deep infection, a DVT and his leg swelled up to twice its normal size. He knows he should get tested because he is sharing needles. I am massively scared that this [sharing needles and contracting hepatitis C] is something that is possible."

Carol was worried about her son contracting hepatitis C, but found it hard to talk to him about the issue:

"Yes, I was worried about him getting it... I used to check that [my son was] not sharing needles. But he denied being on drugs!"

However, not all family members were worried about the risk of their family member contracting hepatitis C. For Sue, the worry of hepatitis C is not as great as some of the other problems she is facing with her son.

"I'm not worried about it because the aggression from my son far outweighs the hepatitis C. He knows the risks and I know the risk. If those are risks which he is prepared to take, then that's for him to decide. For me, it is more about managing his drug use and putting in boundaries when he is abusing the steroids; that's the priority."

Testing

Many family members turned this worry into encouraging their loved one to get tested for hepatitis C, often as part of a wider message of harm reduction.

“Currently, he has had negative hepatitis C tests. He was told to wait another three months for the next test – not that he is tested every three

months – but he has shared with me that he has been tested over the years. I raised it with him as something he needs to do if he is sharing needles.”

“Yes, we’ve had discussions about it. I’ve told him how unhappy I am about the needle use. I’ve told him about being clean. We’ve discussed the need for hygiene... I like to think that he is good about it. But that doesn’t mean that he is.”

Likewise, Carol encouraged her son to get tested, but acknowledged that she only knows what he tells her:

“I often asked him to get tested and he said he was being tested. I can’t do anything more if he says yes.”

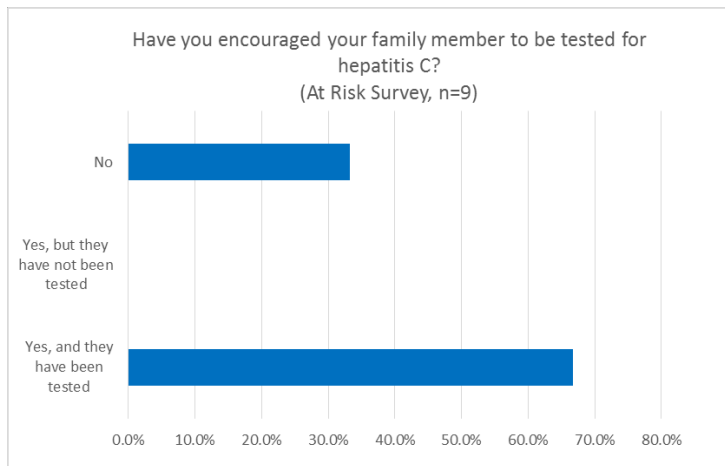
However, Diana did not encourage her daughter to be tested, linking this to the often secretive and hidden nature of drug use.

“I didn’t encourage her to be tested – I didn’t think it would happen. Her using was hidden from us for quite a long time... Maybe the addicts need to get more information as well, because I don’t think she was aware at all about it. She never gave any indication that she knew about it but then addicts hide everything.”

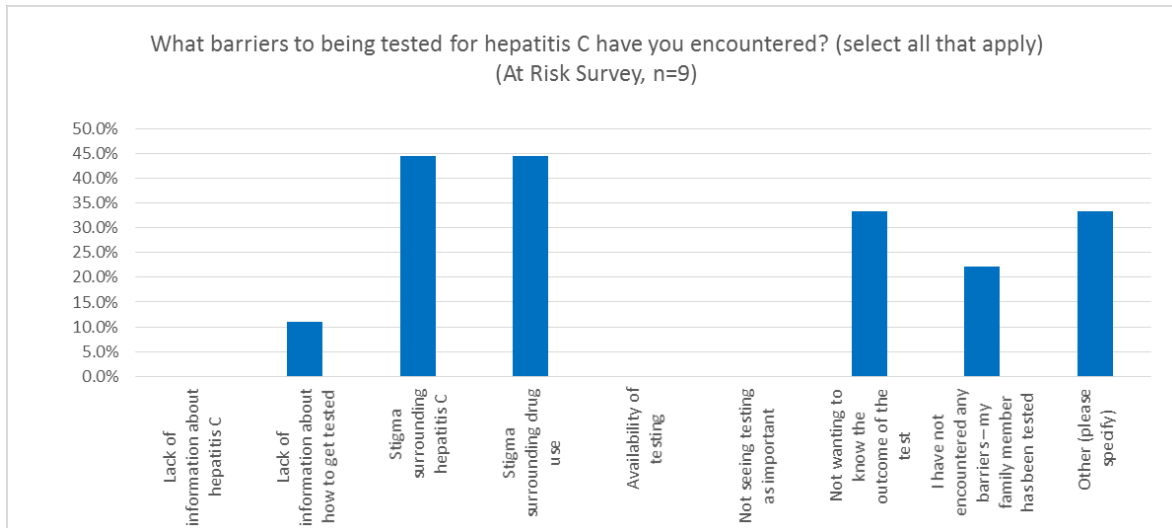
Most of the injecting drug users had been tested for hepatitis C, although two family members were not sure whether their loved one had been tested.

Barriers to being tested

Despite the high proportion of testing for hepatitis C, a number of barriers to being tested were identified. The most common of these were connected to stigma. Amanda described the stigma that her son had experienced from healthcare professionals due to his drug use:



“When he went into hospital, he was dealt with a lot of contempt by a lot of people. He came out homeless – on crutches, with a massive groin injury which needs attending – with nothing in place. I phoned the nurse who discharged him, asking what was the care plan for him, but she said that they have done their bit and he has to get on with it. I have sadly encountered some people – although there have been some wonderful people in his recent experiences – but I have encountered some very disrespectful, unprofessional attitudes. He has been spat at, just because he uses drugs. He told me this was just a window into his world. There is condemnation of people who use drugs.”



A third of participants cited their loved one not wanting to know the outcome of the test as a factor, with one person describing their loved one’s *“fear related to health anxiety”*. This was also the case for Amanda’s son:

“He’s probably really scared of finding out [if he has hepatitis C] and the dangers of sharing if he found out.”

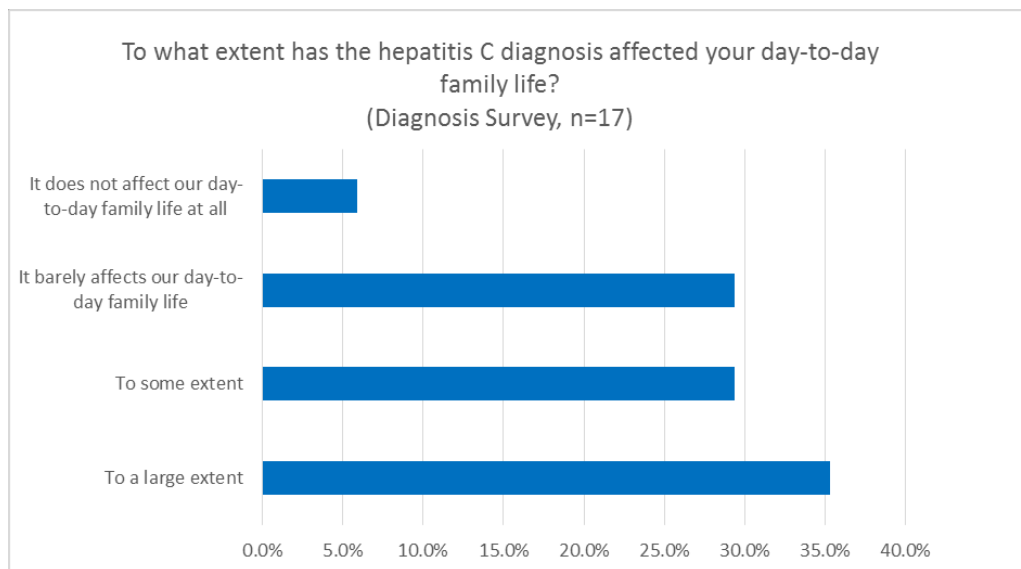
Interestingly, one survey participant linked the rationing of direct-acting antivirals (DAAs) to a reluctance to find out the results:

“Lack of tolerable treatments for those without late-stage liver disease... I’d rather not know. I’d rather not test until the better treatments are available to all.”

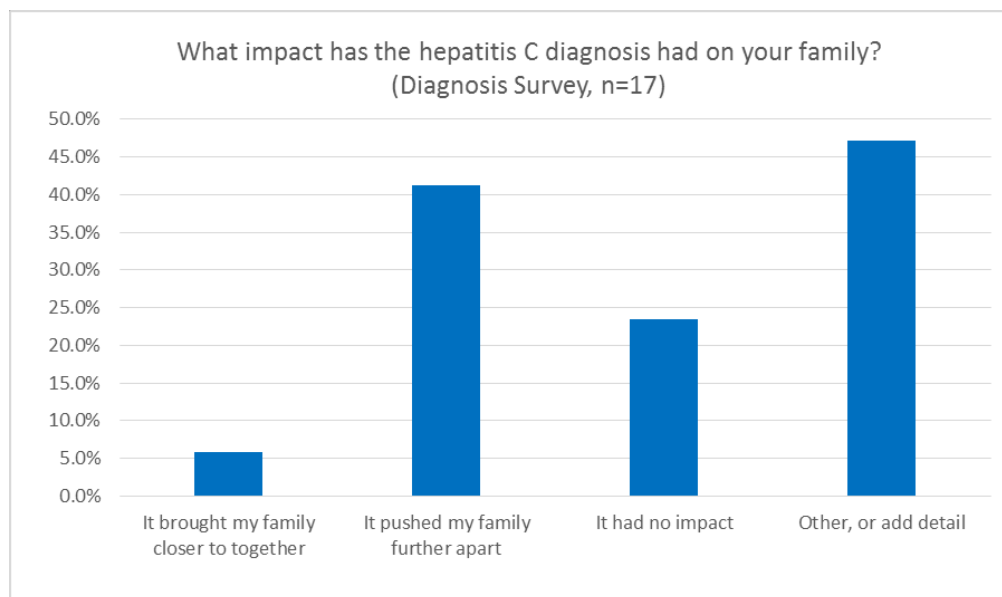
Amanda went on to point out that, for her son, being tested for hepatitis C was not something he was particularly concerned about.

“The other obvious point is that when someone is in the throes of that lifestyle, they don’t think rationally as you or I, they don’t see it [testing for hepatitis C] as necessary or urgent – all he needs to know is where to get his next fix.”

Impact on family life



The impact hepatitis C had on day-to-day family life varied among the family members. One said that *“everything changed”* while others said that it barely had an impact.



Seven family members out of the 17 who answered the survey (41%) believed that the hepatitis C diagnosis had pushed the family further apart, whereas only one thought that it had brought the family closer together.

As hepatitis C can be asymptomatic and thus undiagnosed for years, it can cause reminders of previous drug use which people had thought they had put behind them:

“Past drug use from over 25 years ago is impacting now and that is difficult to accept and deal with for him (and me).”

Coping with symptoms of hepatitis C and side effects of medication

For several family members, dealing with the symptoms of hepatitis C and the side effects of medication had a negative impact on family life, with one family member citing *“irritability, tiredness and low mood”*. Due to the hepatitis C diagnosis, one family member had to become a carer for her mother, whilst trying to keep up her fulltime job.

Others mentioned that they now had to support their loved one:

“[I] needed to be with my son when he was ill.”

For those who have lost a loved one to hepatitis C, the impact is only too stark:

“The effects are profound for living with any sort of illness and the effects of him not being here anymore.”

Fears about transmission of hepatitis C

The infectious nature of hepatitis C, often coupled with a lack of knowledge about how it is transmitted, is a source of worry for several family members, and thus has an impact on their actions and how they relate to their family member. One family member described their fear: *“[My] son was very anxious and paranoid that he would catch it. This made me feel really upset and anxious too.”* Another referred to people being made *“separate from family as worried about infection”*. Even information about the transmission of hepatitis C did not alleviate these fears: *“[the] provision of information [was] unable to dispel myths around transmission of HCV [which led to] behaviour change within the family and estrangement of [my] mother from some of her grandchildren.”*

Fears of transmission impacted the way Carol acted when she was around her son.

“I can’t be normal, I know it sounds awful, doesn’t it? When he goes upstairs, I follow him. I am a bit obsessive, making sure everything is cleaned out. That has an impact on you. He’ll come here and have a shower, and it takes me about an hour to clean it afterwards. I tell him that he is filthy and I am ashamed of him. I didn’t use to do that. He has been doing this for 30 years. He asked me to take him to the hospital, and I told him that I’m not going to, that he is filthy and that he is embarrassing. It’s not a normal life, is it?”

She also described how she had to be tested for hepatitis C herself after she cut herself on her son’s razor when cleaning the shower, shortly before he told her that he had contracted hepatitis C.

“When he told me [that he had hepatitis C], I was devastated. I had cut myself on his razor when I was cleaning the shower a couple of weeks before he told me. I went straight to the doctors to get tested. I was really embarrassed. I know

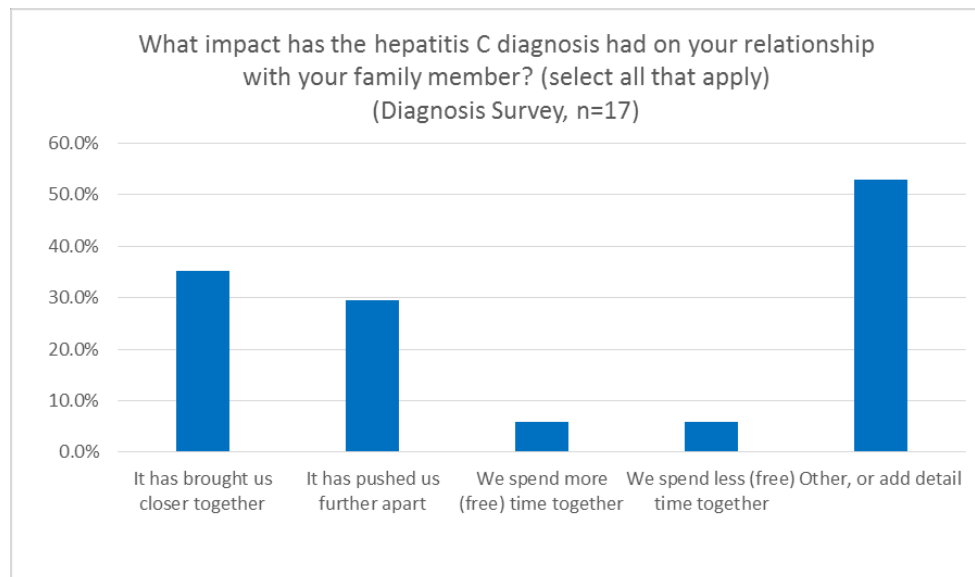
the receptionist from the local village and didn't want her to know. I was tested for hep C and HIV and had to go and have another one because sometimes it lies dormant, and thankfully I was fine. It's not very nice, is it? And the stigma, the stigma's still there whether you like it or not."

These fears had an impact on the relationships within Diana's family:

"Everyone in my family was quite distraught because we didn't know much about it and when we found out, we found out we might be able to pick it up as well. From me being the mum, I fell out with one of my children, my eldest son, because he was very angry and my daughter is the middle child and we had to look at things in a different light... My eldest son is so angry that he doesn't talk about it and refuses to have a relationship with her which is a bit sad but it's his choice. He refuses to communicate with her at all... He has a child and he doesn't want his child involved in her life because of the drug use and because of the contagious disease."

Relationships within the family

Relationships within the family were impacted by the hepatitis C diagnosis in other ways as well.



Survey participants were split between those who thought it brought them closer to together and those who thought it pushed them further apart. One respondent said that it made no difference to relationships in their family.

Several family members reported feelings of anger and worry, which had an impact on their relationship with their loved one.

"[My son's hepatitis C diagnosis] definitely [affected the relationship] with me and my partner, he is so angry he doesn't say anything... He can't forgive himself. My son didn't tell us until it was too late. I'm stuck in the middle between them."

"I think it just left scars because it is a battle. It's the same journey as any disease such as cancer because you watch them deteriorate. It made me incredibly sad and annoyed and angry. You become intolerant of their illness and them even though they are doing their best to present themselves well. You get the worst side of it because you are one of the only people who knows."

One respondent experienced aggression and domestic abuse from her ex-husband which she put down to the treatment he underwent for hepatitis C. This was *"the final thing that triggered me to divorce him"*.

Dealing with a family member's hepatitis C diagnosis can also be a frustrating experience:

"It's pulled us together but my cousin who has it is using it as an excuse for not wanting to do anything with family or around home... He tells us he has symptoms then goes out with mates. None of us are challenging him but avoiding him now."

This participant went on to explain that their cousin says that he is too tired to do chores because he has hepatitis C, but then puts messages on Facebook saying that he is *"milking it"*.

For John, his partner's diagnosis with hepatitis C impacted the physical side of their relationship.

"It did have quite an effect on the physical side, being aware of someone having a disease in their blood which can be quite easily transmitted. It did cause quite a bit of discomfort and a bit of distance between us for a while at the beginning."

Stigma

There is often stigma surrounding hepatitis C due to its associations with injecting drug use, and this stigma can be experienced by the wider family as well.

Carol was mortified after cutting herself on her son's razor before she knew he had been diagnosed with hepatitis C.

"It was all so embarrassing. It was very, very embarrassing at the doctors. I didn't want the test results going through to the reception. There is doctor-patient confidentiality but the receptionist knows - that's what's embarrassing."

John remembered one specific incident of his partner accessing services:

"I do remember one time years ago when she went to the dentist and when she went in she told him that she was hepatitis C positive and he refused to treat her. This was about 10 years ago. She was very upset about that and was quite embarrassed."

Diana said of her daughter:

"The only person who received any stigma was my daughter. She has been in rehab four times. There was stigma at the drug and alcohol service definitely – she felt very uncomfortable telling them."

Katie described how her husband assumed that he would experience stigma:

"He chose not to tell people because he was afraid of their reaction... He was afraid of being judged. He knew how he had contracted it, and he assumed everyone else knew about how he would have got it... The stigma was in his brain... His family have since said that they would not have cared if he had told them about the hep C. He was a quirky person, he would not have experienced any stigma if he had told people."

While several family members said that they had not experienced stigma from friends or family, they were still reluctant to tell other people, as Carol acknowledged:

"My friends are brilliant, they do know how it has affected me. They come round for coffee mornings and they know they can come and it's clean because they know me. I have good friends. I suppose I wouldn't be telling people I don't know well because I would worry what they are thinking of me."

Other family members worried about the stigma:

"You worry about the stigma and can't openly share the issue with your friends."

The secrecy could be isolating:

"It's kept as a secret, so I'm the only member of the family who knows."

Katie linked the shame and stigma with a lack of awareness about hepatitis C:

"There's no Elton John for hepatitis C! It's alright to have HIV because it is glamorous and there is treatment and there is Elton John and people wearing red ribbons. There's no-one out there for hepatitis C, it is all really stigmatised."

Katie's story

In September 2016, Katie's husband, Richard, died of liver failure as a result of hepatitis C which he had contracted 25 years previously. He had injected drugs from the age of 18 until his early 20s. He was diagnosed 10 years ago, before Katie met him.

"He told me about it pretty much straightaway when we met," she says. "Originally it had no effect on me at all. It didn't affect him massively apart from being in the back of his brain."

However, after Katie became pregnant with their daughter Amelia, Richard decided to undertake the interferon and ribavirin combination therapy.



"He started it when our daughter was born. That treatment was horrific, I cannot tell you how horrific it is to live with that treatment... It's just the most horrendous version of chemotherapy. He lost teeth, he lost weight, his sex drive etc. It lasted nearly the whole year. It is very hard. And after the end of it, [the hepatitis C] hadn't gone. That was a real blow. [His hepatitis C diagnosis] didn't bother us originally – it certainly didn't bother me originally – but after the treatment it changed everything and changed who he was. And it rocked us. It was a vile treatment and it had a profound and lasting impact on our relationship. We argued like we never argued before. It made us stronger ultimately. It left lasting effects on us, physically, mentally and emotionally. "

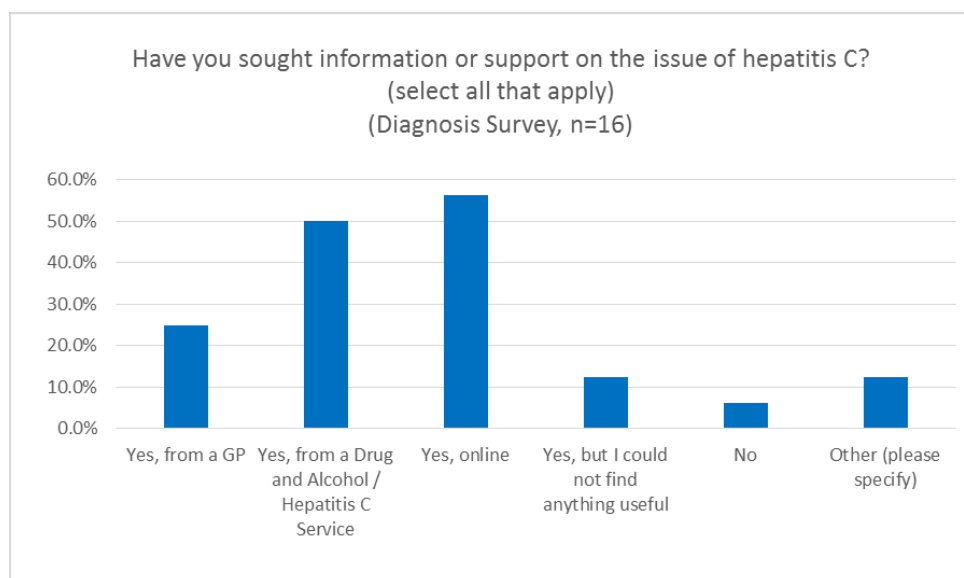
The stress of Richard's treatment took its toll on Katie: "It's emotionally gruelling and tough. It changes you as a person supporting that person. You are on a parallel road, aiming for the same thing but the journey is different – his bumps were not my bumps. It's just a different journey, because you are watching your loved one go through such a difficult time but it is so annoying... I was rubbish with it, I lost weight, I was bolshie and angry. We suffered physically and emotionally in a different way."

In the intervening years, Richard "regained himself" but still had to cope with the symptoms of hepatitis C. In the autumn of 2015, he underwent DAA treatment which cleared the hepatitis C, but by this point his liver was already severely damaged. He chose not to tell Katie the full extent of the damage: "By the time he was admitted to hospital, he hadn't really noticed the full effect. He chose not to tell me the full extent of the damage. He was in so much pain in the last year. He used to hide it and sleep a lot... The latter years with him were fantastic because he chose not to tell me. He was frightened and didn't want to scare me. I was very grateful because we could just live our lives."

"Having hep C is not a trivial thing, being around someone with it is not a trivial thing. It leaves marks and scars on the people around them."

Katie believes that there needs to be more awareness and openness around hepatitis C: "We need to encourage people to be open if a loved one has it... It's a horrible illness and people need to be aware of it. It is a really anonymous illness until it is too late. We need awareness and to be more mindful that it isn't trivial – having hep C is not a trivial thing, being around someone with it is not a trivial thing. It leaves marks and scars on the people around them."

Seeking information and support



While awareness of hepatitis C among families of people who inject drugs was fairly high, many did not know about it in depth and so sought information from elsewhere, most commonly online. Two participants said that they work in the field of addiction and had heard about it through their work.

Experiences of finding information varied. John and his partner had a positive experience:

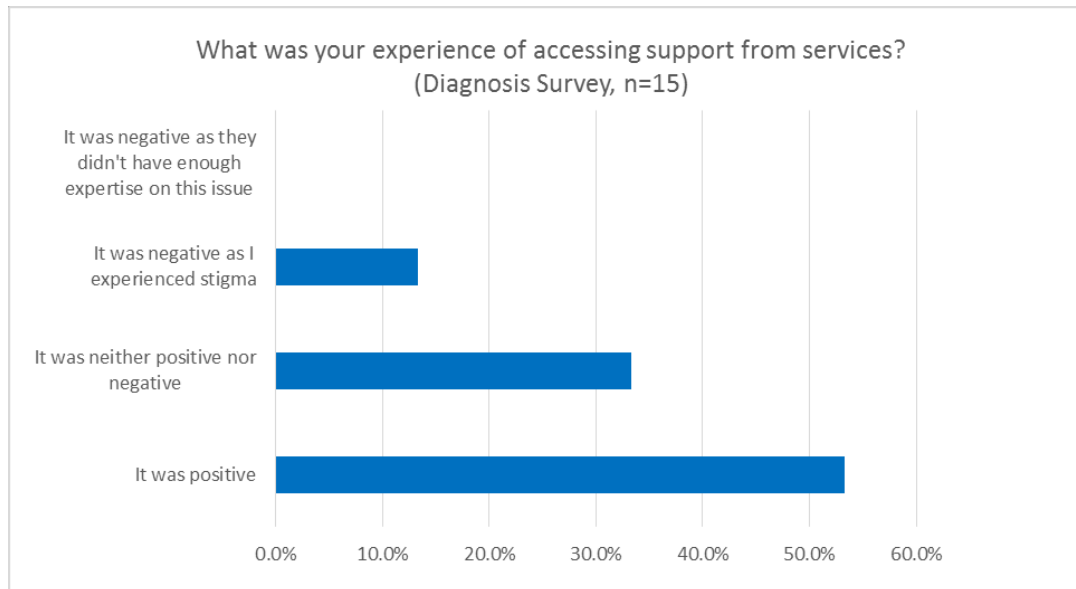
“At first we went to the [sexual health] clinic where we went to get tested. They had a lot of information there, quite a lot of leaflets and booklets... When she started some of the treatment for it, the nurses and the doctor gave quite a lot of information about the disease and the treatment and so on. I went with her one time and I asked questions. I got information from the professionals. We were quite well informed. All the information was quite easy to access.”

While Diana had found information about hepatitis C, it was limited to the basics:

“I’ve done research on the internet and spoken to my GP. It was very basic information though, for example don’t share toothbrushes and razors. I didn’t find too much detail about how the hepatitis gets into the bloodstream and I didn’t understand all the medical side of it.”

Likewise, family members’ experiences of accessing support for their loved one and for themselves were mixed. The most common experience was a positive one, with one participant describing the support as *“very helpful”*. Another participant had a generally positive experience with professionals:

“Great information given online and from professionals around condition and treatment options. Also that cousin is relatively well after scans – he then asked me to leave after this and came out saying they were wrong and he’s really bad. Staff came out to give leaflets.”



However, there were also some negative experiences.

“[There was a] variable response to my mother from staff. Attending Herpetology was unproblematic but my mother felt stigmatised during some of her hospital appointments.”

Another family member described the long wait to see a specialist, which meant that their loved one had yet to access support.

Diana was at a loss as to where her daughter could get support:

“[My daughter] doesn’t know, and I don’t know, any other places where she can get help. There’s help from the GP, I don’t know about drug and alcohol services. She comes in and out of recovery a lot. There’s a blasé attitude about it everywhere. She went into rehab in January. I don’t think even they were bothered. In the rehab she went in, they didn’t seem to be interested.”

On the other hand, both John and Katie acknowledged that there may have been more support out there, but their partners did not want to engage with it.

“I think she probably was offered a counsellor but she didn’t engage with it or anything. She just sort of got support from the healthcare staff and from me and some of the family. She kept it quite private. She didn’t really tell a lot of people, just a few people.”

“From my understanding, I used to moan that there was no support from the liver unit. But they did try to get him in between appointments – he just didn’t go to them. He just went in and out for his treatment, and the nurses tried to get him in for other support but in between he didn’t engage with it.”

Support for themselves

None of the family members involved in the research had accessed support for themselves specifically around the issue of their loved one’s hepatitis C diagnosis.

John felt that he had enough support from his family:

“No, I didn’t [access support for myself]. I think I was offered counselling as well – it was quite a long time ago. I remember going to get the diagnosis and you do get help and are offered support but I was OK with my family and with my partner.”

Diana found that attending a family support group helped her:

“I go to Al-Anon and I find that very helpful. Because it starts off with alcohol anyway. It’s very difficult because you don’t want to talk about it. I can go to Al-Anon and talk about it because everything you say is confidential. I have been going there on and off for about ten years.”

However, this is in contrast to the lack of support she felt she had from her friends and others in her family:

“I don’t mention it with friends. I do have a friend who is a psychiatric nurse and she understands a great deal and it is nice to talk to her. She listens and helps in what she says. But the rest of the family don’t know. I couldn’t tell my brother. He is a very professional person and he just wouldn’t understand it. He doesn’t understand her being a heroin addict anyway. It’s kind of like a secret, isn’t it?”

Katie said that she did not look for support, but would have accepted it if she had been offered it:

“I originally read up on it. There aren’t a huge number of hep C groups, they are pretty few and far between. There aren’t many groups nearby. My life is busy, I’m pretty bright and I self-manage myself. We were pretty good at figuring it out and just getting on with it. If someone had come to me and offered support, I would have said yes, but I didn’t look for it. It’s like living with someone with cancer treatment but covered in a cloud of shame and secrecy. There isn’t that level of resources and support and acknowledgement of this kind of illness.”

Accessing treatment

The majority of family members in our research said that their loved one had accessed treatment after being diagnosed. They were asked what treatment their loved one received, and of those who specified treatment, there was a mixture of those who had had interferon-based treatments and those who had accessed the newer

drugs. Two respondents said that their loved one is currently undergoing treatment, while another three said that their loved one was waiting for treatment. Diana described the delays to her daughter receiving treatment:

"It was only the other day that I spoke to the GP about hepatitis C (we both have the same GP). He referred her in October but she hasn't heard anything. He said he would refer her again. There was no sort of follow up or anything like that."

Two family members said that their loved one had dropped out of the treatment process, one because they said they were too tired to go to the appointment, and another because their loved one had health complications. Another said that their loved one had been successfully treated, but had later been re-infected.

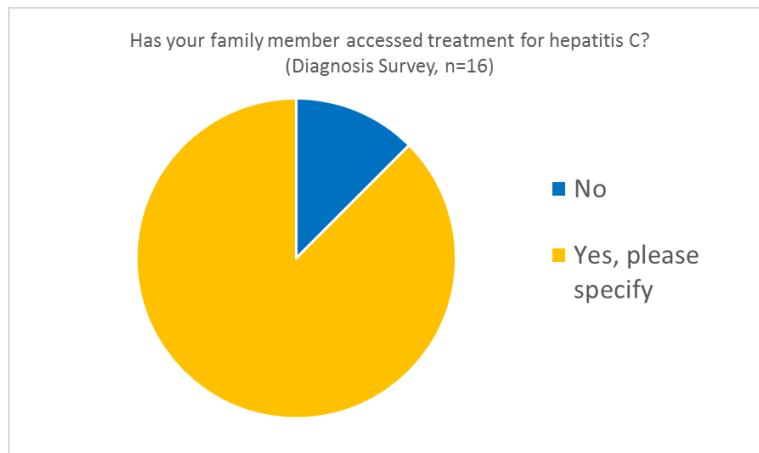
Involvement in treatment

Several family members said that they had been involved in the treatment process, attending appointments or being aware of what was going on.

"I did go with her for a few hospital appointments. At the beginning of the treatment and for the last one when she got the results back at the end, I went along with her."

"The GP is very helpful for her and for myself. He seems to have a lot of patience with her. He takes time and I've often been in the surgery with her."

"I was involved enough to know it was going on. We just carried on living. We didn't sit there and focus on it."



While not being directly involved in her son's treatment, Carol still encourages him to keep it up:

"I still check on him to check he is having his treatment."

The effects of treatment

Treatment for hepatitis C – particularly the older, interferon-based versions – can have a significant impact both on the individual and on those around them.

John recalled the interferon treatment which his partner successfully underwent:

"It was a six month period and it was tablets every day and once a week an injection which she did herself. I remember it was tough but we had already been warned... It's quite a difficult treatment and I know it has quite a few side effects... [She had] depression as well as the other side effects. Sleeplessness. She had hair loss and stomach aches and feeling flu-like. It used to be worse on the day when she had the injections, one day a week."

Watching his partner go through this was hard for John too:

"At the time it was quite depressing really because there was nothing really I could do to help the symptoms. It was upsetting at the time."

Likewise, Katie's husband's experience of unsuccessful treatment was very negative:

"It [interferon and ribavirin treatment] was horrific. I just think it is a barbaric treatment... It involved horrific weekly injections. It was endurance testing, psychologically difficult. It physically ruins them at the time and afterwards."

Improving families' experiences

All of the family members who were involved in this research were asked how the experiences of families of people who inject drugs and have contracted – or are at risk of contracting – hepatitis C could be improved. Their recommendations can be split into five broad areas.

- 1. Promote a greater awareness of hepatitis C among the general public to encourage testing and challenge stigma, through a national campaign and more information in healthcare settings.**

While all the family members involved in our research had some awareness of hepatitis C, many recommended that steps be taken to improve the awareness of the general public. Several linked this to a reduction in stigma:

“Nationwide campaigns to challenge stigma and to highlight that treatment is far more successful these days than was the case seven or eight years ago.”

“There needs to be more awareness and less stigma, more people in the press being open about it.”

Likewise, several family members thought that more coverage in the media would help:

“Education could help, maybe more adverts on the TV about it.”

“You don’t hear much about hepatitis C on television and radio – the media don’t get involved in it. There’s never anything about hepatitis C. You do get stories about heroin and drug use but no-one talks about hepatitis C. More information and the public knowing more would be very helpful. Certainly in my case I knew nothing.”

Others suggested having more information about hepatitis C in GP practices:

“More info displayed in clinical areas. Leaflets, posters etc.”

“Anything that is going to educate people, anything that is going to be put in doctors’ surgeries, information leaflets in places where people can see them, advertisements on websites; anything that can give people an education around it.”

One participant noted that those who have not injected drugs for a long time are in danger of being uninformed due to not being in touch with services, as well as being reluctant to remember their previous lifestyle. Increasing the awareness of the general public may help reach this group of people and their families.

2. Provide information about hepatitis C to family members of people who inject drugs.

As well as greater awareness among the general public, many family members said that there should be information about hepatitis C provided specifically to family members of people who have contracted – or at risk of contracting – hepatitis C. Suggestions included leaflets or a family pack.

“Families need to be educated in their own right so that they provide informed and appropriate support and responses to their loved ones and keep everyone concerned safe.”

“I think family members would benefit from being informed, especially that hep C is no[w] completely treatable and that the treatment is no longer something to be feared.”

Where children are involved, Diana stressed the vital role that grandparents play:

“Grandparents are the answer – in my case my grandchildren were helped by myself... Grandparents are the ones who can help but they also need the information.”

Several family members linked an increase in information with a reduction in fears about transmission:

“A relatives’ leaflet so I don’t under or over react e.g. washing cutlery.”

“Offer of support to wider family to dispel myths.”

3. Enable family members to be more involved in the treatment process.

Several family members said that being more involved in the treatment process would benefit them, as not only would they be more informed, but they would also be in a better position to support their loved one.

“Be part of care/support/recovery plan, be kept in the loop about treatment etc.”

“Anything that is going to educate or involve family members with what is happening would be good.”

One participant did acknowledge the need to gain the patient’s permission to do this:

“The families/family members of those living with hepatitis C would first need to be identified and the permission of the person in treatment obtained to involve them in treatment/care planning before they can appropriately support their loved one.”

Other participants emphasised the need to encourage people with hepatitis C to seek the support of their family:

“Help for the person with hep C to consider the benefits of involving family members. This is not openly discussed in our family and I fear that this attitude just adds to the stigma and shame that those diagnosed feel.”

Suggestions for involvement in treatment included offering to copy letters about appointments to family members so they can make sure their loved one attends and encouraging family members to attend appointments with their loved one.

“It would be good for the whole family to go and see he is having treatment and bring it out in the open.”

One participant related how they had not been involved:

“We were not given information as we were not involved with his key-work sessions and the drug service. We only found out due to a hospital admission.”

4. Provide support for families in their own right.

As well as providing support for their loved ones, family members felt that they needed support for themselves as well. Support groups and peer support were mentioned by a couple of people:

“Support groups for family members would be really good. There are support groups for people with hep C but [I don’t know] of ones for family members. I have been to [a] hep C [group] with my daughter which was helpful.”

“Peer support network, so that family members can speak to other family members.”

This would no doubt help to alleviate the loneliness and isolation experienced by many family members.

“It is not easy, especially when one does not want the family to know: an extra burden.”

“As a parent I don’t feel so alone knowing that there are other parents going through the same thing. It takes away that loneliness – it’s one hell of a lonely journey this.”

This support should be accessible to all family members, regardless of whether or not their loved one wants to involve them in the treatment process:

“Family members of people at risk of contracting hepatitis C because they inject drugs should be offered support and information in their own right as I do not feel it is appropriate that they are left uninformed or unsupported if the drug user does not want them involved in their treatment planning.”

One participant referred to the financial implications of supporting a loved one with hepatitis C and said that there is currently little support for working families.

5. Improve access to treatment for hepatitis C.

Several family members referred to the limited access to the new treatments for hepatitis C and the negative impact that delays to treatment have on the wider family.

“Treatment is available, but [it is] severely limited and seems to be based upon a post[code] lottery. It is extremely distressing [for] the individual and their family not knowing when and if treatment will ever be available.”

“Families have to support their loved one while they wait for treatment, this is very distressing for all concerned, particularly as the new class of drugs will clear the infection in most cases. No one can give any indication of how long the wait for treatment is.”

“There needs to be more of this new treatment available – you shouldn’t have to be at death’s door.”

One family member, who had contracted hepatitis C herself, praised the treatment itself, but said that the after-care was *“almost non-existent”*.

Positives already happening

However, some family members did recount positive experiences, and did not have specific recommendations. John’s partner was successfully treated for hepatitis C and they both found the hospital and staff very helpful:

“From my experience, the hospital were very good. They gave us a lot of leaflets and booklets. The staff were very helpful. If you are proactive and want to find out things and ask for help, help was available. I can’t think of anything else they could provide... the hospital and the NHS provided really high quality care and treatment. She was lucky because the treatment did work.”

Another family member acknowledged that in many cases it is up to the individual to use the services:

“It depends on the person, you only know what they tell you or let you attend. I think if services are used they are excellent.”

Conclusion

It is clear from the family members involved in our research that hepatitis C does not just affect the person who has contracted it; it can have a large impact and wide-reaching consequences for the whole family. More needs to be done in terms of keeping families informed, involved and supported as they in turn support their loved ones along their hepatitis C journey. In this exciting era where the possibility of eliminating hepatitis C as a public health threat is becoming ever more realistic, it is crucial that the voices of the family members behind the scenes do not go unheard.

We would like to thank Gilead Sciences Ltd for supporting this report with an educational grant. Gilead has had no editorial involvement in this publication.

Adfam
2nd Floor
120 Cromer Street
London
WC1H 8BS

Telephone: 020 3817 9410
Email: policy@adfam.org.uk
Twitter: @AdfamUK

www.adfam.org.uk

